

Consumer-Directed Transformation to a Recovery-Based Mental Health System

by

Daniel B. Fisher, M.D., Ph.D.

Judi Chamberlin

National Empowerment Center, Inc.

Definition of recovery. In a recovery culture, peer support will be seen as the central focus of the services and supports. Peers can transform both the individuals they are helping and those around them. It will be important for consumers/survivors to take the lead because they have the greatest commitment to real change. Although the term “recovery” has come into the lexicon of Federal, State, and local reports and plans, there is a concern among consumers/survivors that the meaning of recovery has been subverted.

The first example of what we call a limiting version of recovery appeared in the rehabilitation literature of the early 1990s (Anthony et al., 2002). These authors contend that mental illness is analogous to a spinal cord injury. According to this limiting version of recovery, people with mental illnesses, like people with a spinal cord injury, can learn to cope with their illness but they will never fully recover from a mental illness.

On the other hand, consumers/survivors and researchers have experienced, researched, and written about complete recovery from mental illnesses. (Harding et al., 1987; Karon & VandenBos, 1981; Ahern & Fisher, 2001). This we will call genuine recovery. The National Empowerment Center (NEC) has described the path to genuine recovery—the empowerment model of recovery. According to this model, people with mental illnesses can completely recover by taking control of the major decisions of their lives and thereby assuming or resuming major social roles. We emphasize the importance of this distinction because it lies at the heart of the transformation of the system. If the vision of recovery really means limited recovery, the services will still be designed to control a consumer's major decisions for the rest of his or her life. A system based on a goal of limited recovery is a system with no exit points. It is a system that is always run from the top down by administrators, doctors, and other clinicians who perpetually make decisions for the consumer.

However, it is important to emphasize that, in the NEC definition of full, genuine recovery, people may continue to experience symptoms or may choose to use medication. The hallmark of genuine recovery is the individual regaining control of his or her own life and filling valued social roles. The Empowerment Model illustrated in Figure 1 is based on the research findings that genuine recovery is possible for most people labeled with mental illnesses (Ahern & Fisher, 2001). Given the right mix of resources, relationships, and attitudes, people with mental illnesses can fully recover by (re)gaining

control of the central decisions of their lives, learning to live with intense emotions, and developing the skills and relationships needed to establish a major social role.

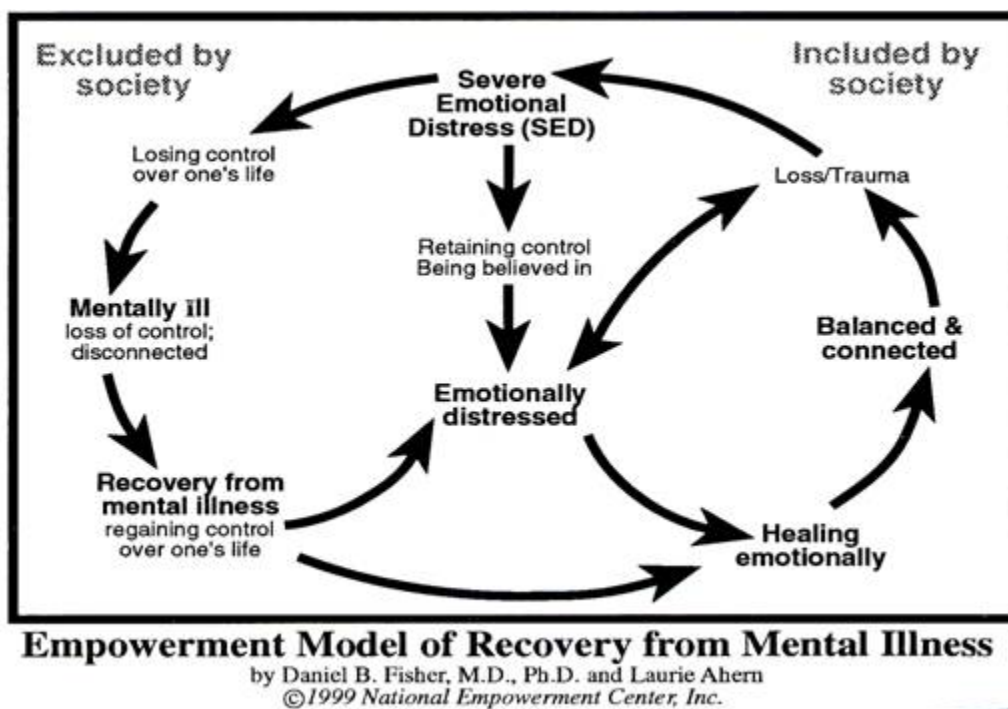


Figure 1

Most people begin life at the right side of the model (Figure 1), balanced and whole. However, we all suffer trauma and loss, which leads to emotional distress and feelings of fragmentation and not being whole. Through coping strategies and social supports, most people are able to heal emotionally and indeed develop a stronger sense of self. Sometimes, however, a major trauma or loss, such as a move to college or the loss of a loved one, can lead to severe emotional distress. At that point (at the top of the diagram) it is crucial that sufficient noninstitutional supports and coping strategies be available to allow the person to heal. During this period, it is also vital that the person retain his/her connections with his/her community and as much control over his/her life as possible. In the absence of supports, such as people who believe in him/her, housing, finances, and coping strategies, the person's life and controls are taken over by institutional mental health systems and programs, and she or he is labeled severely mentally ill. Once a person is labeled with mental illness, he or she must recover not only from the severe emotional distress, but also from the role and identity of a person with mental illness. The label not only relegates people to a low status and diminished rights, but also eats away at their confidence and initiative to pursue dreams and to lead full lives of their own choosing. Consumers/survivors have united around the goal of genuine recovery as outlined in this Empowerment Model.

The report of the Subcommittee on Consumer Issues to the New Freedom Commission (www.mentalhealthcommission.gov) described genuine recovery very well:

Mental health research shows that people can and do fully recover, even from the most severe forms of mental illness. Most fundamentally, recovery means having hope for the future, living a self-determined life, maintaining self-esteem, and achieving meaningful roles in society. Most consumers report they want the same things other people want: a sense of belonging, an adequate income, a way to get around, and a decent place to

live. They aspire to build an acceptable identity for themselves and in the community at large. These are the essential ingredients of recovery from mental illness.

Recovery as an organizing principle. An emerging literature on the success of the recovery approach comes from the self-help movement, testimony of consumers, the psychiatric rehabilitation community, and research. Public and private sectors of the mental health community are initiating recovery-based programs, services, and self-help technologies to overcome the barriers faced by people living with mental illnesses in America. Recovery is an organizing principle for mental health services, programs, and supports that is based on consumer values of choice, self-determination, acceptance, and healing.

For recovery to take place, the culture of mental health care must shift to a culture that is based on self-determination, empowering relationships, and full participation of mental health consumers in the work and community life of society. To build a recovery-based system, the mental health community must draw upon the resources of people with mental illnesses in their communities.

It is widely recognized that changing the mental health system to be more responsive to consumer needs requires the participation of consumers at all levels of policy planning and program development, implementation, and evaluation. Meaningful involvement of consumers in the mental health system can ensure they lead a self-determined life in the community, rather than remaining dependent on the mental health system for a lifetime. A recovery-oriented mental health system embraces the following values:

- Self-determination
- Empowering relationships
- Meaningful roles in society
- Eliminating stigma and discrimination

View the entire article at:

<http://www.mentalhealth.samhsa.gov/publications/allpubs/NMH05-0193/default.asp>